**April 2006** 

# **Improving Long-Term Care Services in Tennessee:**

**Me**eting the Changing Needs of a Growing Population

**Prepared for AARP Tennessee** 



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# Improving Long-Term Care Services in Tennessee:

# Meeting the Changing Needs of a Growing Population

# **Executive Summary**

AARP Tennessee commissioned a study examining the status of the long-term care (LTC) system in Tennessee, analyzing "best practices" from other states' LTC systems and recommending actions to improve Tennessee's system. This study was conducted over a period between September 2004 and December 2005 using data from local and national sources, and from interviews and meetings conducted in-person and by telephone with Tennessee state and local leaders.

AARP has conducted opinion research of its members in a variety of states and the findings are clear regardless of the state: Older adults want to be able to have a choice about which LTC services they receive and where those services are delivered. A huge majority want to receive services in their own homes or in a residential setting such as an assisted living residence; very few want to receive services in a nursing facility.

# Tennessee's Current System and Opportunities for Change

Older adults in the State of Tennessee receive a variety of long-term services and supports aimed at keeping them healthy and independent. In addition to vital supports given them by family and friends and community organizations, Tennessee government has a range of programs aimed at older adults needing long-term services.

There are many ways to evaluate how a state is meeting the needs of its citizens requiring long-term services and supports. One way is to look at reported data on services provided and settings where those services are delivered. In Federal Fiscal Year 2004, Tennessee spent over \$1 billion in Medicaid funds for nursing facility services, while spending just over \$6 million for home and community-based services (HCBS) programs (Waiver and home health) for older adults and adults with physical disabilities. In percentage terms, 99.4% was spent on nursing facility care compared to .6% for HCBS. This makes Tennessee **last in the country** in its percentage spending on HCBS (Gold, 2005).

Another way to evaluate how a state is meeting the needs of its citizens for long-term services and supports is to analyze what it has achieved using the Centers for Medicare and Medicaid Services' (CMS) description of the "key building blocks of coherent systems management" of long-term services: access; financing; services; and quality. CMS has used this analysis repeatedly in describing state efforts to rebalance their long-term support systems (CMS, 2003b).

Specific recommendations for improvement are included below and in the report. However, the **Governor should begin by developing and implementing programs which reflect legislative action**, such as Senate Joint Resolution 57 (2005), which states in part that Tennessee should have a "long-term

**NOTE**: Long-term care and long term services and supports are used interchangeably in this report. An increasing number of individuals with disabilities prefer the term "services and supports" because they believe they don't need to be "cared for"; they just need "services and supports" to help them.



care system which offers Choices for Care to individuals and their families". This includes "the entire range of care and support from respite care in the home and adult day care services to care in residential settings, including assisted care living facilities" and "eliminates artificial barriers and funding biases through the creation of a global LTC budget or other mechanism" (SJR 57).

# **Access**

The first key building block is improved access to comprehensive information and assistance and simplified eligibility. Individuals need information on services at critical times and government needs to make timely decisions on program eligibility to allow people to know about all their LTC service options. People often move to nursing facilities because they are unaware of alternatives or cannot piece together disjointed community services into a coherent program that can help them remain at home. Tennessee does not regularly and uniformly give LTC program information to people either in a hospital or early in their stay in a nursing facility.

Tennesseans currently receive information about LTC services and supports through a variety of means: web sites; toll-free telephone numbers; written publications; and personal contact. However, in assessing the availability of information and assistance as a whole, there is no well-defined and broadly understood way for individuals and families to obtain comprehensive information through any single means. Applying for and receiving available LTC services requires individuals and families to coordinate with a number of different government entities.

Many states have developed "single entry points" (SEPs) for LTC services which meet these needs for information and counseling at various times and places. Tennessee has taken significant initial steps in establishing such a resource for its residents, including investment in building a statewide resource database. Most recently, the Tennessee Commission on Aging and Disability applied for and received a three-year federal grant to develop two regional model Aging and Disability Resource Centers (ADRCs). These Centers will serve as the basis for expansion statewide and for the development of a more comprehensive program.

# Tennessee should:

- 1. Continue the development of a single entry point (SEP) system through the Tennessee Commission on Aging and Disability and the Area Agencies on Aging and Disability. An SEP should be designated for a specific local area where people can access information about LTC services, receive counseling about options and service availability, assessment of need, and eligibility determination for public programs. The SEP and its database of LTC resources should also be able to be accessed electronically and coordinated statewide. SEP staff should travel to people seeking assistance rather than requiring people to come to a specific site.
- 2. Continue the development of a client assessment instrument that focuses on the need for supports that address activities of daily living as much as medical needs. That instrument should be geared to electronic data collection which determines program eligibility, develops plans of care for nursing facility and community-based care, and links with existing program and finance information systems.
- 3. Ensure that information is available for people in need of LTC services at hospitals and a short time after admission to a nursing facility so that people understand their LTC options. Eligibility determination needs to be done much more efficiently, so that people receive timely notice if they qualify for public programs. This can be accomplished in many ways, including through a "fast track" process or using a form of presumptive eligibility where an individual could begin receiving HCBS pending a final determination of financial eligibility.

4. Develop a post-admission nursing facility assessment process for Medicaid residents and those soon to be eligible for Medicaid which informs individuals and families of HCBS options and assists people who want to have services delivered in another setting. This process should begin no later than 30 calendar days after facility admission. Responsible entities must be designated and be accountable for assisting people to leave facilities, and transition costs need to be funded as necessary.

# **Financing**

The second key building block is to create a seamless funding system supporting individual choice. For Tennesseans to have real choices about where they receive needed LTC services, financing must be available to support their decisions. When individuals decide that they want LTC services delivered in their home, arranging those services should proceed efficiently without professionals wondering if there are enough dollars in the "home-delivered services" budget to support those individual choices.

A number of states have adopted "unified" or "global" LTC budgets where both institutional and HCBS monies are combined in one budget and managed by one entity. The question then becomes whether there is money in the entire LTC budget rather than whether there is enough money in any specific line item of a budget.

Tennessee currently has two budgets for Medicaid LTC services, one for institutional services and one for waiver and crossover services. This brings the challenge mentioned above of ensuring that there is enough money in a specific budget and an HCBS Waiver slot available when a person wants to receive services at home. The good news is that both budgets are managed within one entity, TennCare's Division of Long-Term Care, making it less complicated to manage the budgets and Waiver slots to ensure that financing is available to guarantee individual choice.

# **Managed Care**

Some states have chosen to adopt a managed care approach to long-term care service delivery. Those states have chosen to contract with organizations to manage all or part of the Medicaid LTC benefits and cover all or part of disability-specific populations. The reasons for doing this have been both for more effective care delivery and for monetary savings. Although most of the managed LTC programs are still relatively small, there are notable examples of monetary savings and customer satisfaction. Many of the states that have programs are expanding and other states are now developing new programs.

Tennessee is now developing its own managed LTC pilot program in Davidson and Knox counties, choosing both urban and rural locations for its initial implementation.

# **Individualized Budgets**

A number of states have adopted systems of individualized budgets where Medicaid LTC enrollees actually have control over a specified amount of money allocated for their needs. There have been adequate safeguards adopted to ensure financial integrity and the health and well-being of the individuals in the programs. The demonstration programs were rigorously evaluated and the outcomes were deemed successful enough that the Centers for Medicare and Medicaid Services (CMS) adopted a new HCBS Waiver program, Independence Plus, to facilitate more states adopting the model. Although it appears that Tennessee may be moving forward on this concept for its Medicaid enrollees with mental retardation/developmental disabilities through a 2003 CMS-funded grant, there is little active discussion of this concept for older adults and adults with physical disabilities.



# **Methods to Ensure Budget Neutrality**

State policy makers are appropriately concerned about the potential costs of allowing greater individual choice of services and settings. The concern most often voiced is that as current long-term care financing is being shifted to follow an individual's desire to be served in the community, new people requiring new financing will be admitted to nursing facilities.

Most, if not all, of the states described in this paper, which have made investments in building their capacity to serve older adults and people with disabilities in community settings, have seen and continue to see decreases in their Medicaid nursing facility utilization rates.

Some of the methods that states have used to ensure the budget neutrality of a rebalanced system are:
1) combining institutional and home and community-based care budgets; 2) combining provider payment across a variety of acute and long-term care settings; 3) instituting budget and waiver caps; 4) preventing the addition of Medicaid-certified nursing facility beds; and 5) converting nursing facility beds to community care facilities. As discussed in this paper, these strategies have proven successful.

# Tennessee should:

- 5. Designate a lead entity and fund an ongoing program to educate residents about individual financing of long-term services and supports. The program should use a broad variety of educational media to target younger, working-age adults with a focus on savings and insurance programs, and older adults with a focus on health promotion and disease prevention and cost-effective home and community-based services.
- 6. Develop a plan for a unified long-term services expenditure budget that is flexible enough to allow an eligible individual to choose where to receive LTC services and supports. Although TennCare manages both institutional and HCBS Waiver budgets, it needs to develop mechanisms which allow easy transfer of monies from facility care to HCBS, and provide enough Waiver slots and services for individuals who want care delivered outside nursing facilities.
- 7. Continue development of the managed LTC pilot program and rigorously evaluate the impact on the population it serves. Special attention must be focused on timely access to needed services, the quality of the services delivered and appropriate consumer safeguards.
- 8. Develop a statewide Medicaid HCBS Waiver program which enables individuals to direct their own service providers and have control over a specified budget.

# Services

The third key building block is ensuring that needed services and supports are available across settings and provider types. There must be an adequate menu of HCBS and enough providers to deliver those services, including services and supports that are not funded through Medicaid, such as housing.

# **Service Types**

Tennessee Medicaid provides a variety of home health services, but does not cover, as other states, optional personal care services to help people who require assistance with activities of daily living (ADLs) such as bathing, dressing, eating and mobility. Those who qualify for Medicaid LTC benefits are entitled to receive services in a nursing facility, but must receive special approval to have services delivered at home through Medicaid's HCBS Waiver program. While Tennessee offers a modest array of waiver services, most states have a wider array of available services.

Those who don't qualify for Medicaid, need LTC services, and want to receive those services at home can be served by the state-funded Options program. Unfortunately, this program has a waiting list of more than 4,000 individuals.

# **Service Providers**

When discussing service providers, the family caregiving resource must be included. The term family caregiver refers to unpaid individuals such as family members, friends and neighbors who provide care and can live with the person cared for or live separately. There are an estimated 34 million caregivers providing care for someone over 50 (National Alliance for Caregiving and AARP, 2004) and an estimated 80% of homecare services are provided by family caregivers (U.S. Agency for Healthcare Research and Quality, 2000).

It is vital for states to develop ways to support this valuable and much-needed caregiving resource. States utilize the federally-financed National Family Caregiver Support Program which provides services to caregivers of adults over 60. In Tennessee, the respite and supplemental services components of this program are in high demand, but are very limited by budget.

Many state Medicaid programs are now also compensating family members, except parents and spouses, for delivering HCBS. They are utilizing both their HCBS Waiver programs and "individualized budgeting" programs to accomplish this. This is one viable method for increasing the number of reliable, paid in-home caregivers, but it is obvious that more needs to be done in Tennessee to support this family resource.

It is hard to gauge the extent to which Tennessee has a problem with an adequate supply of providers of HCBS services. Although the TCAD maintains that there is a shortage of available providers for home care and personal care throughout the state (TCAD ADRC grant application, 2005), the extent of the need is difficult to assess since Tennessee has only really expanded its HCBS opportunities in the last few years.

# Housing

Housing is a serious issue for states that seek a balanced LTC system for a variety of reasons. Many individuals who want to remain at home often need their home to be "modified" after a fall, stroke or a progressive illness, but either do not have the resources to make these modifications or can't get permission from a landlord to do so. For those who need more care, there are often community-based group living arrangements that can meet their needs. Once again, however, individuals may not be able to afford to pay for the housing, in addition to paying for needed services.

Many state Medicaid programs pay for "assisted living" services. While states vary in how they define these services, they are all connected with community-based group housing arrangements that can be made affordable for people with limited resources. Tennessee Medicaid does not currently cover these LTC services in its HCBS Waiver program.

# Tennessee should:

9. Adopt a variety of methods to encourage and sustain family caregiving through means such as compensating relatives for caring for their loved ones, providing in-home respite care and other supportive services, including caregiver training and education. The State should add assistive equipment/technologies to its Waiver services and utilize the existing minor home modification service whenever needed to allow an individual to continue to receive needed services in their home. Assistive technologies could include cost-effective items such as controls

- to turn lights on and off, eating utensils and door handles that are easy to grip and alarms which alert people when there is danger from leaving a stove on in a kitchen or when people are at the door or calling by phone.
- 10. Include assisted living, in-home respite care and adult day care services in the HCBS waiver and develop a limited personal care option in the Medicaid State Plan focused on people who need this service to maintain their independence in their homes.
- 11. Designate one public entity with the responsibility for recruiting and retaining needed LTC providers. Too often this responsibility is spread among various entities with predictable inefficient results. The State should utilize a variety of mechanisms, including enhanced reimbursement, to develop needed provider capacity.
- 12. Provide increased reimbursement for providers of home care services. Home is where the huge proportion of Tennesseans want to live as they age. Home care workers and their agencies must be reasonably compensated, supported with training and publicly acknowledged for their important work.
- 13. Develop affordable, accessible "housing with services" and other community living models and make that development a State priority. A lead entity must be designated and given the responsibility of ensuring that specific numbers of units are developed.
- 14. Ensure affordable and accessible transportation options in both rural and urban areas. People must be given the opportunity to be active members of their communities and be able to access friends and other supportive community entities. These activities help older adults and adults with physical disabilities remain healthy.

# Quality

Quality is the final key building block listed by CMS for coherent systems management of long-term care services. This report makes no assessment on the quality of care delivered either in nursing facilities or by HCBS providers. The discussion on quality is more focused on whether the state has sufficient structures in place to monitor the quality of services. The state of Tennessee licenses providers and monitors quality of care in nursing facilities, where most LTC services are currently provided. It also licenses the home health agencies which deliver a large percentage of the publicly-funded HCBS. The Tennessee Commission on Aging and Disability (TCAD) and the Area Agencies on Aging and Disability are responsible for monitoring the quality of HCBS Waiver services and TCAD has recently developed new policies related to quality of care and has developed an enrollee handbook, a provider operations manual and a quality assurance manual.

In order to address quality assurance and improvement, some states have focused their attention more on system performance indicators, while others have focused on consumers' perception of quality.

# Tennessee should:

15. Continue to develop systems designed to monitor quality and to detect and resolve problems in the LTC system, especially in the HCBS program. The consumer's voice must be brought into the evaluation of HCBS quality, as well as all other LTC settings, and Tennessee should explore using the Participant Experience Survey for this purpose. Appropriate data and management systems must be developed to support a quality assurance/quality improvement program.

# Improving Long-Term Care Services in Tennessee: Meeting the Changing Needs of a Growing Population

# Introduction

AARP Tennessee commissioned a study examining the status of the long-term care (LTC) system in Tennessee, analyzing "best practices" from other states' LTC systems and recommending actions to improve Tennessee's system. This study was conducted over a period between September 2004 and December 2005 using data from local and national sources, and from interviews and meetings conducted in-person and by telephone with Tennessee state and local leaders.

Over the past few years, AARP has conducted opinion research of its members in a variety of states and the findings are very similar regardless of the state: Older adults want to be able to have a choice of what type of LTC services they receive and where those services are delivered. A huge majority want to receive services in their own homes or in a residential setting such as an assisted living residence; very few want to receive services in a nursing facility. A very recent AARP survey of Tennessee registered voters age 35 and over revealed that 95% said having LTC services to enable them or their family members to stay at home as long as possible was extremely important (40%), very important (44%), or somewhat important (12%) (AARP Tennessee Voter Survey, 2006). This corresponds very closely with recent AARP member surveys in Mississippi and Oklahoma where 94% believed it very important (80%) or somewhat important (14%) to have LTC services that would enable themselves or their family members to stay at home as long as possible (AARP Mississippi and Oklahoma Surveys, 2004-05).

AARP member surveys also identified that older adults were concerned about getting quality, understandable information about LTC options and having a choice of settings in which to receive services, if they were not able to remain at home (AARP Member Surveys, MS and OK 2004-05). It is apparent what people want and, as discussed below, many states have responded to individuals' desires to have information about and choice of LTC services and settings.

Tennesseeans want LTC services at home

**84%** extremely or very important

12% somewhat important

# The Current Long-Term Care System in Tennessee

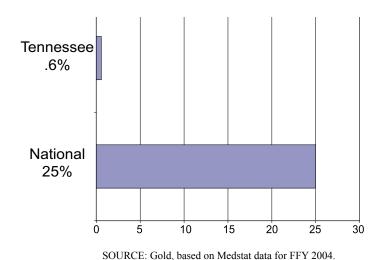
Older adults in the State of Tennessee receive a variety of long-term services and supports aimed at keeping them healthy and independent. In addition to vital supports given them by family and friends and community organizations, Tennessee government has a range of programs aimed at adults needing long-term services, including Older Americans Act Programs, Medicaid and Medicaid Home and Community-Based Services (HCBS) Waiver Programs, a state-funded HCBS program, a Program for All-Inclusive Care for the Elderly (PACE), licensure of facility-based and other service providers and a limited amount of housing, transportation and other economic and social programs.

There are many ways to evaluate how a state is meeting the needs of its citizens requiring long-term services and supports. One way is to look at reported data on services provided and settings where those services are delivered. In Federal Fiscal Year 2004, Tennessee spent over \$1 billion in Medicaid funds for nursing facility services, while spending just over \$6 million for HCBS programs (Waiver and home health) for older adults and adults with physical disabilities. In percentage terms, 99.4% was spent

# FIGURE 1

# **Medicaid Expenditures for HCBS**

- Older Adults and Adults with Physical Disabilities -



6 III

on nursing facility care compared to .6% for HCBS. This makes Tennessee **last in the country** in its percentage spending on HCBS (Gold, 2004 data).

Another way to evaluate how a state is meeting the needs of its citizens for long-term services and supports is to analyze what it has achieved using the Centers for Medicare and Medicaid Services' (CMS) description of the "key building blocks of coherent systems management" of long-term services: access; financing; services; and quality. CMS has used this analysis repeatedly in describing state efforts to rebalance their long-term support systems (CMS, 2003b).

# FIGURE 2

# Coherent Systems Management Access Comprehensive information, simplified eligibility, and single access points Individual Living in the Community Philosophy of self-direction and individual choice Services Responsive supports across settings and practices Responsive supports across settings and practicerypes

SOURCE: Adapted from Lutzsky, S.: Key Building Blocks in Designing a System in Which Money Can Follow the Person. September 2003.

# **Access**

# Information and Assistance

Tennesseans can receive information about long-term care services and supports through a variety of means: state and local web sites; local and toll-free telephone numbers; written publications; and personal contact. The Tennessee Department of Human Services, the Bureau of TennCare and the Tennessee Commission on Aging and Disability (TCAD) all have information on their web sites about long-term care services. TennCare's site has a definition of long-term care (LTC), explains that services are provided through nursing homes and home and community-based services (HCBS), explains that a Pre-Admission Evaluation must be approved, describes the kinds of HCBS available and gives a toll-free number to contact for more information. There could easily be much more comprehensive information on this site. The TCAD web site has much more detailed information on a variety of LTC services, but its only mention of nursing facility care is a link to Medicare's *Nursing Home Compare* web site. It also gives a toll-free telephone number for more information, a number different than TennCare.

At the local level, almost all of the Area Agencies on Aging and Disability have web sites. While they vary greatly in the amount and variety of information, they all have good information about services, local and toll-free telephone numbers for more information, and physical places people could go to get more information. This report does not attempt to analyze the quality of information given by personal contact, only the availability of that contact.

In assessing the availability of information and assistance as a whole, there is no well-defined and broadly understood way for individuals and families to obtain comprehensive information through any single means. People really need to know what information they seek and be willing to spend a lot of time searching written data sources and talking to people on the telephone. It is apparent that there is currently no coordinated method for publicizing these available resources. However, the TCAD has applied for and received a three-year federal grant to develop two regional model Aging and Disability Resource Centers (ADRCs) which can serve as the basis for expansion statewide and for the development of a more comprehensive program.

# Counseling

Giving people comprehensive and helpful information at crucial times should be a goal for all state LTC systems. While many states are understandably focused on disseminating LTC information before a person actually needs LTC services, attempting to get people to plan for the future, most people seek information when they need it. Sometimes, LTC needs result from a progressive illness or the "natural" aging process. This group of people can seek information over a period of time. But very often, LTC needs result from a specific occurrence, like a fall, stroke or heart attack. A typical scenario is that individuals are hospitalized, their conditions are stabilized, and they and their families are told that hospital discharge will occur within 48 hours. This is the point at which people need to know where to call for information and have someone knowledgeable and available to help them discover the available options. Often a person may be able to immediately return home with visits from a home health nurse and/or aide, but unless people have that information, returning home may not even be considered.

LTC counseling about options for services and settings is crucial. It should be readily available to the public and information should be understandable so that people can have real choices about LTC. Counseling should be available in people's homes or at hospitals and nursing facilities. It should include a full assessment of people's capacities, where they may need help and how they can access that help.

Many states have developed "single entry points" for LTC services which meet these needs for counseling at various times and places. A more detailed description follows later in this report, but Tennessee has currently no such resource for its residents.

The Tennessee Commission on Aging and Disability (TCAD) received a three-year grant from the U.S. Administration on Aging and the Centers for Medicare and Medicaid Services to develop two regional model Aging and Disability Resource Centers (ADRCs), one at the Greater Nashville Area Agency on Aging and Disability (AAAD) and one at the AAAD in East Tennessee. These ADRCs can serve as the basis for expansion statewide. The goal is to have a visible Access Point for anyone who needs support services for an elderly person or a person with disabilities to get access to a full range of information, assistance and a wide range of services through telephone, web site and personal contact. Plans include improved information data bases, which are already under development, and enhanced ability to access public programs (TCAD ADRC grant application, 2005). This is a hopeful development for Tennesseans and resources should be focused in this area to realize these goals.

# **Program eligibility**

Access to public LTC programs in Tennessee is not easy. Local Area Agencies on Aging and Disability offer access to a range of services through federal Older Americans Act programs such as nutrition programs, homemaker, personal care and chore services, similar programs for more impaired adults through the state-funded Options for Community Living (Options) program and other services through the Medicaid HCBS Waiver program including case management, homemaker, personal care, minor home modification, personal emergency response systems, home-delivered meals and institutional respite care. While there are openings available in the Medicaid HCBS Waiver program, eligibility determination is a complex and time-consuming process, creating a significant barrier to receiving timely services. There is a long waiting list for the Options program and waiting lists for certain Older Americans Act programs as well.

The Tennessee
Commission on
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Access to Medicaid requires application at one of 95 county-based offices of the Department of Human Services (DHS). DHS is responsible for making decisions on whether a person is *financially* eligible for Medicaid and also has responsibility for determining eligibility for food stamps and rehabilitation services. If a person needs LTC services, TennCare has the responsibility to determine if the services are *functionally* necessary and is the entity which authorizes nursing facility care or HCBS. Tennessee is not the only state where decisions on LTC services are made by two separate entities; however, as described above, often people need to make time-limited decisions about LTC services and settings and not knowing if they will be eligible for programs like Medicaid and HCBS limits their choices. An increasing number of states are using "presumptive" financial eligibility determinations, where an eligibility determination is made after an interview or short written disclosure about an individual's income and assets. A final decision is made later when all the necessary documentation has been received, but people can begin receiving HCBS immediately, avoiding unneeded institutional stays. In December 2005, TennCare announced its own new presumptive eligibility policy which will have the effect of paying for HCBS from the first day of Medicaid eligibility instead of the thirtieth day (TennCare Media Release, 2005).

Additionally, when TennCare makes its assessment of functional need for LTC, it uses an evaluation instrument called the PreAdmission Evaluation for Nursing Facility Care (PAE). The initial assessment

is normally done by a provider, a doctor or nurse often employed by a nursing facility, and reviewed by TennCare. Many believe this form and process, developed to set a threshold for nursing facility admission, establish an institutional care plan and to determine institutional reimbursement, has made it easier for an individual to receive institutional services rather than HCBS (TennCare Grant Application, 2004). Tennessee is in the process of completing development of a new assessment form and process that will be designed for both facility services and HCBS, to determine program eligibility using both medical and non-medical needs, and support individual choice. This will be an improvement for the entire LTC process and should expedite eligibility. As this report is being published, it appears that Tennessee will

A new
assessment form
and process will
improve access
and expedite
eligibility.

adopt a new PreAdmission Evaluation shortly and that it will address functional, cognitive and behavioral, and medical assessment for needed services, regardless of the setting in which they are delivered.

# **Financing**

# **State Budgeting**

For Tennesseans to have real choices about where they receive needed LTC services, financing must be available to support their decisions. When individuals decide that they want LTC services delivered in their home, arranging those services should proceed efficiently without professionals wondering if there are enough dollars in the "home-delivered services" budget to support those individual choices. Many states have separate budgets for institutional services and HCBS. Many have those separate budgets managed in different state entities. Most have a defined number of Medicaid HCBS Waiver "slots" which can only be expanded by executive and/or legislative action.

As discussed below, a number of states have adopted "unified" or "global" LTC budgets where both institutional and HCBS monies are combined in one budget and managed by one entity. The question of financing individual choice then becomes less complicated. The question is then whether there is money in the entire LTC budget rather than whether there is enough money in any specific line item of a budget. Obviously, it is much easier to track one budget than multiple and there is a corresponding efficiency in ensuring that individuals get the services they need, where they want them.

Tennessee currently has two budgets for Medicaid LTC services, one for institutional services and one for waiver and crossover services. This brings the challenge mentioned above of ensuring that there is enough money in a specific budget and a HCBS Waiver slot available when a person wants to receive services at home. The good news is that both budgets are managed within one entity, TennCare's Division of Long-Term Care, making it less complicated to manage the budgets and Waiver slots to ensure that financing is available to guarantee individual choice.

# **Managed Care**

Some states have chosen to adopt a managed care approach to long-term care service delivery. Those states have chosen to contract with organizations to manage all or part of the Medicaid LTC benefits and cover all or part of disability-specific populations. The reasons for doing this have been both for more effective care delivery and for monetary savings. Although most of the managed LTC programs are still relatively small, there are notable examples of monetary savings and customer satisfaction. Many of the states that have programs are expanding and other states are now developing new programs.



Tennessee is now developing its own managed LTC pilot program in Davidson and Knox counties. It has selected BlueCare to manage the pilot areas and is working with a broad-based Advisory Committee in the development of a Medicaid waiver necessary to implement this program.

# **Individualized Budgets**

A number of states have adopted systems of individualized budgets where Medicaid LTC enrollees actually have control over a specified amount of money allocated for their needs. There have been adequate safeguards adopted to ensure financial integrity and the health and well-being of the individuals in the programs. The demonstration programs were rigorously evaluated and the outcomes were deemed successful enough that the Centers for Medicare and Medicaid Services (CMS) adopted a new HCBS Waiver program, Independence Plus, to facilitate more states adopting the model. Although it appears that Tennessee may be moving forward on this concept for its Medicaid enrollees with mental retardation/developmental disabilities through a 2003 CMS-funded grant, there is little active discussion of this concept for older adults and adults with physical disabilities.

# Services

This is an obvious "building block" for a balanced LTC system. There must be an adequate menu of HCBS and enough providers to deliver those services. In analyzing service adequacy, it is important to look at both state and federally-funded HCBS and who provides them, and also at services and supports that are not funded through Medicaid, such as housing.

# **Service Types**

Even for those individuals who don't qualify for LTC services, Tennessee Medicaid provides a variety of home health services including part-time nursing services, home health aide services, medical supplies and equipment, physical and occupational therapy, speech pathology and audiology services. These services can be provided as long as they are medically necessary for the individual. Many states also include a Medicaid optional personal care service (not federally-required) to help people who require assistance with activities of daily living (ADLs) such as bathing, dressing, eating and mobility.

Those who qualify for Medicaid LTC benefits are entitled to receive services in a nursing facility, but must receive special approval to receive services in the home and community through Medicaid's HCBS Waiver program. The statewide waiver for HCBS for older adults and adults with physical disabilities began operating in February 2004 and currently still has openings for eligible Tennesseans. Waiver services include case management, homemaker services, personal care, minor home modifications, personal emergency response systems, home delivered meals and institutional respite care. Although this array of services is

a decent beginning, most states have a wider array of available services to support individuals at home and in community settings. Tennessee should certainly consider adding in-home respite services, assisted care living facilities, adult day care and assistive technologies to the Waiver services package.

Those who don't qualify for Medicaid, need LTC services, and want to receive those services at home can be served by the state-funded Options program. The Options program provides information and assistance, homemaker services, personal care and home-delivered meals. These services assist many people who need LTC to continue to live at home. Unfortunately, this program currently has a waiting list of more than 4,000 individuals.

# **Service Providers**

When discussing service providers, the family caregiving resource must be included. The term family caregiver refers to unpaid individuals such as family members, friends and neighbors who provide care and can live with the person cared for or live separately. There have been many studies completed which estimate both the number and economic value of family caregivers. A 2004 study estimates that there are 34 million caregivers providing care for someone over 50 (National Alliance for Caregiving and AARP, 2004) and another study found that about 80% of homecare services are provided by family care-

givers (U.S. Agency for Healthcare Research and Quality, 2000). Additionally, recent research found that 78% of adults needing LTC and living in community settings rely **solely** on family and friends (Thompson, 2004). Research on the economic value and impact of family caregiving include: over \$257 million a year market value of unpaid care provided (National Family Caregivers Association, 2003); both male and female children of aging parents report modifying work schedules and altering work-related travel (MetLife Institute, 2003); caregiver spouses who provide 36 or more hours of care a week experience depression or anxiety six times higher than non-caregivers; caregiving children twice as high as non-caregivers (Cannuscio, others, 2002).

Nationally about 80% of homecare services are provided by family caregivers.

It is vital for states to develop ways to support this valuable and much-needed caregiving resource. All states take advantage of the federally-financed National Family Caregiver Support Program, part of the federal Older Americans Act, which provides services to caregivers of adults over 60. In Tennessee, this includes information about services, assistance in getting services, individual and group counseling and training, respite (relief) care, and supplemental services to support services already being given by the caregiver. Respite and supplemental services are in high demand, but limited by budget and to those who care for individuals with at least two limitations in activities of daily living (ADLs).

Many state Medicaid programs are now also compensating family members, except parents and spouses, for delivering the same HCBS services described in this report. They are utilizing both their HCBS Waiver programs and "individualized budgeting" programs to accomplish this. This is one viable method for increasing the number of reliable, paid in-home caregivers, but it is obvious that more needs to be done in Tennessee to support this family resource.

It is hard to gauge the extent to which Tennessee has a problem with an adequate supply of providers of HCBS services. Although the TCAD maintains that there is a shortage of available providers for home care and personal care throughout the state (TCAD ADRC grant application, 2005), the extent of the need is difficult to assess since Tennessee has only really expanded its HCBS opportunities in the last few years. However, all states are challenged to secure an adequate supply of trained HCBS caregivers and many have initiated a variety of programs aimed at this issue.

# Housing

Housing is a serious issue for states that seek a balanced LTC system for a variety of reasons. Many individuals who want to remain at home often need their home to be "modified" after a fall, stroke or a progressive illness, but either don't have the resources to make these modifications or can't get permission from a landlord to do so. For those who need more care, there are often community-based group living arrangements that can meet their needs. Once again, however, individuals may not be able to afford to pay for the housing, in addition to paying for needed services.

Many state Medicaid programs pay for "assisted living" services. While states vary in how they define these services, they are all connected with community-based group housing arrangements that can

be made affordable for people with limited resources. Tennessee Medicaid does not currently cover these LTC services in its HCBS Waiver program. Additionally, state services programs have been working with their state housing counterparts to address these issues in a variety of ways including new construction, rehabilitation, and rent subsidies and preferences for older adults and individuals with disabilities.

# Quality

This report makes no assessment on the quality of care delivered either in nursing facilities or by HCBS providers. The discussion on quality is more focused on whether the state has sufficient structures in place to monitor the quality of services. The state of Tennessee licenses providers and monitors quality of care in nursing facilities, where most LTC services are currently provided. It also licenses the home health agencies which deliver a large percentage of the publicly-funded HCBS. The Tennessee Commission on Aging (TCAD) and Disability and the Area Agencies on Aging and Disability are responsible for monitoring the quality of HCBS Waiver services. The TCAD has recently developed new policies related to quality of care and have developed an enrollee handbook, a provider operations manual and a quality assurance manual. These are good steps in trying to achieve high quality services. Much more needs to be developed to ensure quality of services, but the state has made progress given the HCBS Waiver program was only implemented in 2004. A regular survey of consumer feedback on services received should be added to the program as soon as possible.

# **Opportunities for Enhancing Tennessee's System**

Even though the state of Tennessee is developing a number of new programs that have the potential for improving the system which supports the long-term needs of people with disabilities of all ages, there are many additional things it could do to improve and enhance its system and prepare for an increasing elderly population. This paper will explore opportunities for Tennessee to enhance its long-term system of supports and services by utilizing CMS' key building blocks for coherent systems management referenced above (access, financing, services, and quality) and describing examples where states have developed systems CMS publicizes as "promising practices" (http://www.cms.hhs.gov/promisingpractices).

# State Actions on Rebalancing Long-Term Care

For many years numerous states have undertaken initiatives to "rebalance" their long-term supports and services system. The "balance" they are trying to achieve is one between resources spent on institutional services and those spent on home and community-based services. Nationwide, as in Tennessee, more public dollars are now being spent on long-term services in home and community settings than in past years. In the Medicaid program nationally, by far the largest public long-term supports program, the percentage of all long-term service dollars spent on home and community-based services has risen from about 14% in 1991 to about 36% in 2004 (Eiken & Burwell, 2005).

Before looking at some of the actions that states have taken to rebalance their long-term care systems, it is instructive to briefly discuss the reasons why states have taken these actions.

1. The Americans with Disabilities Act (ADA) and the U.S. Supreme Court decision in <u>Olmstead</u> The concise interpretation of this decision is that individuals with disabilities covered under the

ADA cannot be institutionalized if they want, and are able, to receive appropriate support services in a community setting, subject to the reasonable financial limitations of a state. Many states have taken rebalancing actions since this decision, some because of litigation.

# 2. Consumer Demand

For many years, consumers and their advocacy organizations have argued that needed services could be delivered to an individual in a variety of settings and that people should not be forced to go to an institution as the only way to receive services. Many have also argued that community services are less expensive than institutional services. Additionally, advocacy organizations argued that publicly-supported consumers ought to have the same opportunities as people using private funds to receive services outside institutions.

# 3. Financial and Philosophical Concerns

A number of states had engaged in planning efforts focusing on long-term care systems that would meet the amount and quality of services needed to serve the "baby boom" generation. Early reports focused on the year 2010; later reports mostly on 2020 and 2030. From those planning efforts, two major themes evolved: it would be extremely expensive to build sufficient institutions to meet the population's demand for services; and that the "boomer" generation was not going to easily accept an institutional model and would demand as much freedom and individuality as possible. In addition, current long-term care consumers were also demanding more individualized services and greater control over those services.

# 4. Market Competition

Some state policy-makers believed that the state should establish a "level playing field" and let the providers compete for customers. Many had become tired of the fierce battles over reimbursement by a variety of provider groups and by charges of favoritism. Others believed that competition would increase both quality and cost-effectiveness and that consumer demand and expectations would be better satisfied.

# **Key Building Blocks**

### Access

The first key building block in a rebalanced long-term support system is improved access to comprehensive information and assistance and simplified eligibility. Access to information about long-term care programs, qualification for those programs and streamlined eligibility determination for needed

services are vital components in a system. Unless people understand their options and receive timely notice of program eligibility, they cannot have a real choice of services and the settings where they are received. People often move to nursing facilities because they are unaware of the alternatives, cannot afford the alternatives without some public financing or cannot piece together disjointed community services into a coherent program that can help them remain at home.

# Coherent Systems Management KEY BUILDING BLOCKS

- Access
- Financing
- Services
- Quality

(See Figure 2, page 8)

Many states have begun to address these challenges by offering a coherent source of information, in one place, about all the long-term support services available and how to access them. Some states offer both information **and** assistance, such as crisis intervention, help with eligibility determination, contacting providers, choice and benefits counseling, or protection and advocacy. Some states have adopted "single entry points" either for all community programs regardless of funding source or all community and institutional programs. Such single entry points may include authority to enable admission to programs. A few states have combined all these elements into "comprehensive access" that offers a truly personcentered way of streamlining access to all aspects of a long-term support system.

As noted above, it is not easy for Tennesseans to find comprehensive information about long-term services and receive assistance and counseling about their need for service. There is also no program for giving people needed information at critical times, such as when they are being discharged from a hospital, and there is no established program to expedite eligibility determinations for people needing support from public programs. Below are examples of what some states have done to improve their residents' access to long-term services and supports.

# Washington

Washington is an acknowledged leader in providing home and community-based services as an alternative to institutionalization. It has been developing its comprehensive single entry point system over many years. Until a few years ago, the Aging and Disability Services Administration (ADSA), an administration within the Department of Social and Health Services (DSHS), served the needs of older adults and adults with physical disabilities. It now also serves individuals with mental retardation/developmental disability.

The single entry point (SEP) system was implemented at the local level for all publicly-funded services. State employees at local offices throughout the state offer thorough information on all publicly-financed programs and offer similar information through its web site. A person can apply for cash assistance, food assistance, medical assistance, nursing home, assisted living or in-home care and alcohol and drug treatment at the SEP.

If a person is applying for long-term care support, an employee will conduct a level-of-care or functional assessment of the applicant in their home or other location within five (5) working days. However, if an individual is being discharged from a hospital or rehabilitation center or if an applicant resides in the community and is in immediate risk of admission to a nursing facility, the assessment must be performed within one (1) working day of the referral. The assessment instrument is highly technologically-based. The person performing the assessment uses a software program, generally loaded on a laptop, which guides the person through the assessment and then automatically determines whether the applicant meets the required level of care for services and what services can be authorized and develops a plan of care for the applicant. This automated level-of-care assessment is a huge benefit for an applicant and family as they immediately know that if they meet the *financial* qualifications for the program, they will receive a defined amount of services.

Simultaneous with performing the level-of-care (LOC) assessment, the financial eligibility worker, an ADSA employee located in the same office as the ADSA employee performing the LOC assessment, begins the process of determining financial eligibility. Financial eligibility determinations must be completed within 45 days from the time the financial eligibility worker is notified that the applicant is applying, although there is an internal standard to complete the determination within 15 days. Once the applicant's financial information is gathered and entered into the system, the automated technology determines the public programs for which the applicant is eligible (CMS Promising Practices, 2003).

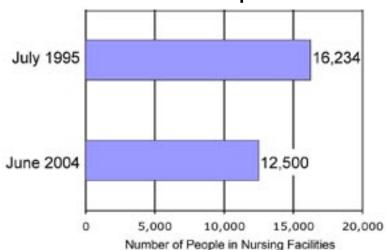
Washington also has a "Fast Track" process where vital home and community-based services can be authorized *prior* to the completion of a formal eligibility determination, if state staff determines that the person will probably be eligible. Services can be immediately authorized up to ninety (90) days if the person applies for HCBS waiver services within the first ten (10) days (CMS Promising Practices, 2003).

Another key part of Washington's system is its Nursing Facility Case Management program. State-employed case managers are assigned to specific nursing facilities where they visit new Medicaid residents and those likely to become Medicaid-eligible within 180 days, within 7 days of admission. They conduct a functional assessment and discuss available HCBS options. If a person wants to receive services at home or in a community residence, the case manager conducts a more comprehensive assessment and works with the facility staff, the individual and family to develop and implement a transition plan (CMS Promising Practices, 2004). One reason why individual choice of settings and services is a real option is that there is an ample supply of community providers and there is no waiting list for Medicaid HCBS.

Washington's system really gives people timely information on services for which they qualify and the amount and scope of those services. Armed with this information, consumers can truly make an "informed choice" about the services they need and the options on where those services can be received. Washington Medicaid was supporting about 12,500 people in nursing facilities in June, 2004, down about 24% from 16,234 reported in July, 1995 (Leitch, 2004). In addition, it is spending about 40% of its 2003-05 long-term care resources on home and community-based services for older adults and people with physical disabilities compared with 18% in 1991-93 (Leitch, 2004). Both represent a large shift in supporting people's desires to live at home and in community dwellings.

# FIGURE 3





Source: Leitch, K.: Money Follows the Person: Where is it?. Presentation to the National Academy for State Health Policy, St. Louis, MO. August 2004.

#### Wisconsin

The state of Wisconsin is also an acknowledged leader and innovator in providing home and community-based services. Wisconsin is piloting perhaps the most extensive new SEP model in the country. Their single entry point (SEP) model is known as the Aging and Disability Resource Center (ADRC). The specifically-chosen name immediately conveys the message that this center is for both older adults and other individuals with disabilities. It also conveys that the center has resources to share with all people who need assistance.

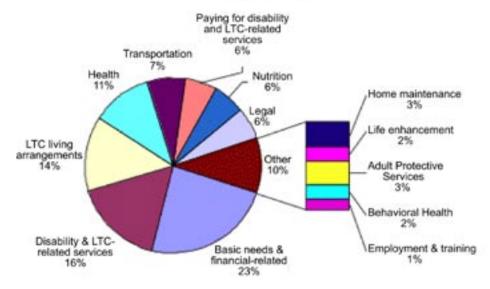
The Resource Centers are a component of Family Care, a redesign of the LTC system in Wisconsin which includes a managed LTC benefit. The Centers are units of county government. They can be contacted in-person or through a 24-hour telephone line. Staff can deliver information in a person's home, if requested, and respond quickly to urgent needs. Staff provides thorough information to anyone who contacts them and offers counseling on factors to consider when making long-term care decisions. They also provide pre-admissions "options counseling" to all individuals entering nursing facilities, community-based residential facilities and adult family homes. The Resource Centers also provide advice on available publicly-funded home and community-based services options and determine eligibility for the HCBS waiver and two integrated health and LTC programs: the Program for All-Inclusive Care for the Elderly (PACE) and the Wisconsin Partnership Program (CMS Promising Practices, 2003).

The Aging and Disability Resource Centers (ADRCs) also offer information on a full array of preventive and community social services available to older adults and individuals with disabilities. Additionally, the staff helps individuals access entitlements such as Supplemental Security Income (SSI), Medicare and Medicaid, and helps them when they encounter problems with those benefit programs.

The Centers have already proven to be a great resource for Wisconsin populations. The call volume alone has greatly exceeded the projected demand for information (CMS Promising Practices, 2003). During calendar year 2003, the nine existing ADRCs handled over 61,000 contacts. People called most often seeking information and assistance related to long-term care services and benefits such as home

#### FIGURE 4

# Resource Center Information Requests by Category, First Quarter 2003



SOURCE: The Lewin Group: An Annotated History of Wisconsin's Aging and Disability Resource Centers. Falls Church, Virginia. October 2003.

support, care management, respite, Medical Assistance, health insurance and long-term care related living arrangements (www.dhfs.wisconsin.gov/LTCare). While this relatively new innovation is being piloted in 9 counties, the state is currently working with local entities to develop *9 more sites* covering 14 counties, selected through a competitive process. The state has made a clear commitment and significant investment in this model and plans to expand ADRCs statewide.

As stated above, the ADRCs are a component of Family Care, a larger redesign of the LTC system in Wisconsin including a managed LTC benefit. In October 2005, an independent assessment of Family Care revealed that the state spent an average of \$452 less per person each month for Medicaid services in the four of five counties with a managed LTC benefit, \$55 less in Milwaukee County, during calendar years 2003-2004 (APS Healthcare, Inc., 2005). This savings was achieved while managed care enrollees continued to be very satisfied with their services (CMO Member Outcomes, 2003-04).

# Colorado

The state of Colorado started a hospital discharge "Fast Track" program on a pilot basis in 1997 to decrease inappropriate nursing facility admissions by establishing eligibility for Medicaid home and community-based services (HCBS) on a timelier basis. Local research had estimated that at least one-third of the people discharged from hospitals could have used HCBS instead of nursing facility services, if those services had been available to them upon discharge from the hospital. Eligibility determination for HCBS was taking at least forty-five (45) days due mainly to lack of documentation of an individual's financial resources (CMS Promising Practices, 2003).

The Fast Track program is a partnership between a hospital, Denver Health Medical Center, the county agency performing the Medicaid financial eligibility, Denver Department of Social Services and the single entry point agency performing the Medicaid functional eligibility, Home Care Management. Although it started on a pilot basis in 1997, ceased operation because of lack of funding, began again in 1999 under a federal Nursing Facility Transition grant which continued for about 15 months and restarted again a few months later, the state now funds an administrative cost of about \$70,000 a year for the program.

Hospital discharge planners identify people who would likely be eligible for Medicaid and who, without HCBS, would otherwise need nursing facility services. The Fast Track Team, composed of a financial eligibility worker, a functional eligibility worker and a "runner", first determine whether a person is already receiving Medicaid. If not, the "runner", whose job is to gather all the necessary financial information from family, friends, and financial institutions, and the financial worker begin to determine financial eligibility while the case manager/functional eligibility worker does an eligibility assessment and develops a plan for community living.

During the fiscal year 7/1/2000-6/30/2001, the average length of time required for eligibility determination was nine (9) days. Even with the Fast Track process, this time period may result in the determination being made after the person is discharged. In these instances, a person could move home or to a community setting with the support of family and friends or be admitted to a nursing facility for a short-term stay. During the time period between March 1999 and June 2001, 234 people had been identified and assessed and 149 of them avoided a long-term nursing stay as a result of the Fast Track process (CMS Promising Practices, 2003).

Colorado chose to implement this accelerated eligibility process at the hospital setting; Washington employs an accelerated process regardless of setting, but concentrates its efforts on nursing home admissions, as does New Jersey. Regardless of setting, accelerated eligibility determination gives individuals real options for deciding where and in what manner they wish to receive services.



# New Jersey

The state of New Jersey developed a program called Community Choice, which offers its nursing facility residents information about home and community-based services and housing alternatives as well as assistance for people who wish to move from the facility. Starting in 1998, the state hired registered nurses and social workers to work with Medicaid participants and people who would likely be Medicaid-eligible within 180 days of entering the facility. State regulations require that nursing facilities notify the state when people meeting these requirements enter their facility. Community Choice also receives referrals from other sources such as Area Agencies on Aging (AAAs), the long-term care ombudsman program, staff, residents and families.

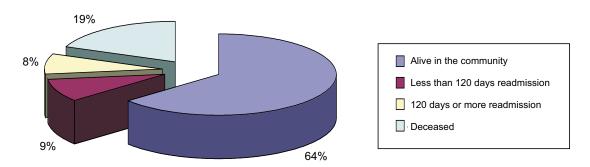
The Community Choice program built upon the work that New Jersey had been doing in its preadmission screening program, which targeted the same Medicaid and potentially Medicaid-eligible participants for screening for the appropriateness of nursing facility placement. In addition, the stateemployed registered nurses performing the screening indicated whether short-stay or longer-term stay was appropriate. State-employed social workers then visited people recommended for short-term stay and discussed options after discharge from the facility. What Community Choice did was to add more resources to this effort, hire and thoroughly train staff to perform the counseling, and standardize the operations on a statewide basis.

The Community Choice counselor assesses the needs of the nursing facility resident and his or her interest in leaving the facility, and then works with the resident, family and friends to identify appropriate housing and services outside the facility. After a person leaves the facility, counselors must make at least two follow-up contacts with the individual to ensure that he or she has the appropriate services and supports. Policy requires a contact between 24-48 hours after discharge and then 14-30 days after discharge. The individual is then asked to contact an AAA office or waiver case manager if additional help is required (CMS Promising Practices, 2003).

Between 1998 and 2001, the Community Choice counseling program helped more than 3,400 people with discharge from a nursing facility. During 2000 and 2001, the program assisted an average of 1,500 people a year. During the same years, nursing facility utilization decreased by almost 1,600 people. Part of the success of the program should be attributed to the fact that New Jersey was simultaneously increasing home and community-based options for older adults and individuals with physical disabilities (CMS Promising Practices, 2003).

#### FIGURE 5

# Nursing Facility Residents' Status One Year After Discharge



SOURCE: Howell-White, S.: Current Living Situation and Service Needs of Former Nursing Home Residents: An Evaluation of New Jersey's Nursing Home Transition Program. Rutgers Center for State Health Policy. May 2003.

More recent figures from September 2005 reveal that 5,583 individuals have been transitioned from nursing facilities since March 1998 (Reinhard & Polansky, 2005) and Medicaid nursing facility utilization decreased from a 1998 average monthly census of 34,064 to a 2004 average monthly census of 30,395, a reduction of 11% (CMS Promising Practices, 2005).

An evaluation of clients discharged through the program in the calendar year 2000 revealed that 77% of the clients were living in a home-based setting, with more than 50% in their own home or apartment. One-third were living alone, while over two-thirds were living with a relative. Only a few clients returned to a nursing home. 86% reported being very satisfied with their living situation and 7% somewhat satisfied. One year after discharge, 64% were alive in the community, 19% had died, 9% had been readmitted to a nursing home within 120 days of discharge and 8% had been readmitted after 120 days. Of those readmitted or deceased, most changes were due to frailty and significant adverse health incidents (Howell-White, 2003).

...5,583 individuals have been transitioned from nursing facilities

...Medicaid nursing facility utilization decreased by 11%

# **Financing**

The second key building block is to create a seamless funding system supporting individual choice. Some states have improved the responsiveness of their finance systems by providing "linkages" between budget categories that are otherwise fixed and inflexible. They have made the financial connection between money spent in separate institutional and HCBS budgets. The Texas legislature directed that money be moved from the nursing facility state budget to the community care programs state budget when an individual transitioned from a nursing facility to community-based services. Wisconsin passed a law specifying that if a nursing facility voluntarily "de-licensed" a nursing facility bed, then a HCBS waiver opportunity could be created and funded without going back through the state budget process.

Some states have combined funding from different Medicaid categories into one flexible funding source that can provide services to an individual regardless of setting. This "seamless" funding really supports individual choice of services and settings so that people get the help they need, when they need it and how they desire it.

Other states have promoted more flexible funding through use of "individualized, self-directed budgets". The individualized budgets afford individuals the opportunity for more discretion over the services they receive.

States are also changing provider reimbursement rates and methodologies and some are using capitated budgets to cover HCBS as well as institutional and/or acute care costs.

Financing is at the core in building a rebalanced long-term services and supports system because money must be available to purchase the needed services in the setting desired by the individual. There are a number of different approaches and methods that states have employed to ensure that financing follows individual choice. CMS categorizes them into state budgeting, reimbursement rates and methodologies, and individualized budgeting.

Tennessee appears to have consolidated the financing of all its Medicaid LTC services within its TennCare Division of Long Term Care. However, the following examples of state budgeting, reimbursement methodologies and individualized budgeting are instructive.



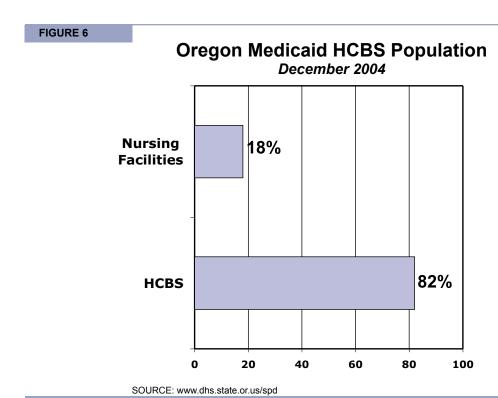
# **State Budgeting**

# Oregon

Oregon has had an integrated state budget for Medicaid long-term care for older adults since 1981 and, a few years later, also for adults with physical disabilities. Merging the budgets for nursing home care with home and community-based services has made it easy for money to follow the person. Having a long-term care budget managed by the same administrative entity has also eliminated any bureaucratic competition for additional funds for individual long-term care programs (i.e. nursing home vs. community care).

Using its single entry point system, individuals receive information and counseling on long-term care options. Individuals can apply for public support and eligibility is determined for a broad range of programs (similar to Washington). An individual's care needs are assessed using a software program. The program determines whether they meet the nursing home level of care and whether their care needs qualify them for Medicaid long-term care benefits. The software also develops a plan of care for the individual including the amount and type of supports that would be available, if the person also meets the financial criteria (similar to Washington). At that point it is very clear that the individual could choose to receive the services in a nursing facility, an assisted living or residential care facility, adult foster home or their own home. A single entry point staff member is available to help the individual and family decide which option best meets their needs. Whatever option is chosen is supported with state and federal financing.

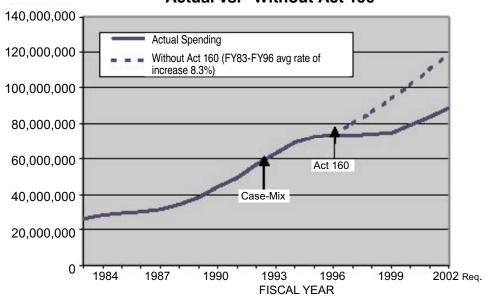
This is clearly the easiest and best model of state budgeting to support an individual's choice of services and settings. While state financial decision-makers are interested in how many people are being served in different settings, the bottom line is how many people are being served and at what cost to the state. From July, 1995 through December, 2004, Oregon reduced the number of Medicaid-supported individuals in nursing facilities from approximately 7300 to 5062, an over 30% reduction (www.dhs.state.



or.us/spd). As of December 2004, it served over 82% of Medicaid-enrolled older adults and individuals with physical disabilities in home and in community-based settings (www.dhs.state.or.us/spd) and spent 70.5% of its total Medicaid long-term care funds on HCBS in federal fiscal year 2004, compared to the national average of 36% (Burwell, et, al. 2005).

### FIGURE 7

# Nursing Home Medicaid Expenditures Actual vs. "Without Act 160"



SOURCE: Vermont Department of Aging and Disability Services Annual Report 2001

# Vermont

In 1996, the Vermont legislature passed legislation which required the reduction in the Medicaid nursing facility budget and an investment in the HCBS budget. Act 160 had four primary goals:

1) improve the state's independent living options for older people and people with physical disabilities;

2) create a climate where Vermonters may live in the most independent, least restrictive environments they choose;

3) decrease the growth of the Medicaid nursing facility budget through the development of consumer options; and 4) redirect nursing facility dollars into HCBS with consumer participation and oversight in the planning and delivery of long-term care services (CMS Promising Practices, 2003).

Vermont began a number of initiatives to achieve these goals. It created ten (10) Long-Term Care Community Coalitions, comprised of consumers and their advocates, providers and local Area Agencies on Aging, and charged them with the responsibility for the planning and coordination of their local long-term care systems. The state asked the coalitions to concentrate on implementing strategies to reduce unnecessary nursing facility and emergency room utilization and find ways to expand and develop new HCBS services, using the savings generated from Act 160. The coalitions continue to meet on a regular basis to determine unmet needs and seek ways to build capacity to meet those needs.

Vermont also changed the way people gain access to the Medicaid HCBS Waiver. The state began to admit people based on need rather than based on the date of their application. The written policy clearly gives priority to four distinct groups: 1) applicants who are in a nursing facility and want to transition out; 2) applicants who are in a hospital and would otherwise be transferred to a nursing facility; 3) applicants in the community at risk of harm without waiver services; and 4) applicants at risk of moving to a more restrictive setting.

Vermont also established a new waiver to offer a Medicaid-funded residential option. The Enhanced Residential Care Waiver provides a wide range of services in a 24-hour licensed care setting to delay or prevent nursing home admission (CMS Promising Practices, 2003).

This example demonstrates what a state can do when it adopts a clear policy and budget strategy and takes action to both develop new community options and prevent unnecessary nursing facility utilization, engaging local and regional stakeholders in the planning and implementation. It was clearly stated that money for new community options was going to come from reductions in existing nursing facility expenditures. It is also an example of how vital it is to develop sufficient amounts and types of community options. Real choice of community supports comes when there are a number of viable options from which to choose.

Between 1996 and 2004, Vermont's percentage of long-term care dollars spent on nursing facilities for older adults and people with physical disabilities fell from 88% to 70%, a substantial achievement over a sustained period of time (CMS Promising Practices, 2004). During that same time period, Medicaid enrollees served by HCBS Waivers grew from 415 to 1188, a growth of over 186% while people served in nursing facilities dropped from 3630 to 3216, almost 13% (Flood, 2005).

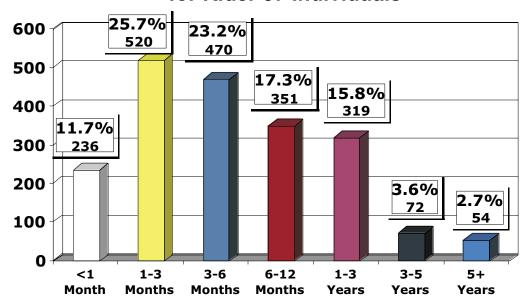
#### Texas

The Texas legislature enacted a two-year appropriations rider (Rider 37) effective September 1, 2001 through August 31, 2003 which allowed the Texas Department of Human Services to move Medicaid funds used to pay for an individual's care in a nursing facility to the Community Care Programs budget when a Medicaid participant transitioned from a nursing facility to a home or community-based residence. The language was simple and the policy straightforward. "It is the intent of the legislature that as clients relocate from nursing facilities to community care services, funds will be transferred from Nursing Facilities to Community Care Services to cover the cost of the shift in services".

Nursing facility residents learned about their option to transition and have the money being spent on them in the facility transferred with them to the community through a letter from the Texas Department of Human Services to all Texas nursing home residents. The letter included written materials about community choices available to them and provided the phone number for their local Texas Community Care Programs office. To qualify, the person must be a Medicaid participant. Once a person indicates a desire to transition, a state case manager assesses the person to ensure that they meet the medical and functional criteria for one of Texas' Community Care Programs. The case manager then works with the person to develop and implement a plan of care for community living. Once eligibility is determined, the person can move to the community and the money for the services will follow as the dollars are transferred from one state budget line to the other (CMS Promising Practices, 2003).

Rider 37 expired on August 31, 2003, but was reauthorized as Rider 28 and remained in effect until August 2005. Most recently, the substance of Riders 37/28 were enacted into law by the Texas Legislature effective September 1, 2005.

# Length of Stay in Nursing Facility for Rider 37 Individuals



SOURCE: Traylor, C.: The Texas Promoting Independence Experience, "Money Follows the Person 1999-Present". Presentation to the Home and Community-Based Waiver Conference. Milwaukie, WI. October 2003.

Through September 30, 2003, there were 2,291 individuals who transitioned from nursing facilities to community care. Under Rider 37 (through 8/31/03), almost 63% of the individuals had resided in the nursing home over three (3) months and almost 40% had been there over six (6) months. Over 66% were over 65 years old, with almost 19% over 85. Most individuals moved to live with family (37%); many moved to assisted living (32%) and a large number moved to their own home (26%) (Traylor, 2003). More recent data from February 2005 reported that nearly 7800 individuals have used the Riders to transition from nursing facility care (The Lewin Group, 2005).

This is another example of a state's enunciation of a clear policy and budget direction which resulted in giving people community options and having money follow the person from institutional to community living.

# **Reimbursement Rates and Methodologies**

# **Managed Care**

# **Texas**

Texas implemented a Medicaid managed LTC pilot program called STAR+PLUS in April 1998 in Harris County (Houston). As of January 1, 2005, it served approximately 65,600 adults who have physical or mental disabilities. The program operates under a combination 1915 (b)/(c) Medicaid waiver, which allows it to provide HCBS in a mandatory managed care environment.

Texas began its managed LTC program to provide better services to its aged and disabled population and reduce expenditures. STAR+PLUS integrates acute and LTC service delivery for its enrollees to ensure coordination between services. One advantage for STAR+PLUS members is that if they have a nursing facility "level of care", they can enroll in the statewide HCBS waiver without being placed on a waiting list, as others in the state must do. The program also provides incentives for dually eligible (Medicare and Medicaid) enrollees to join the Medicare and Medicaid managed care plans offered by the same managed care organization. If they do this, services are more coordinated and they have unlimited access to medically necessary prescriptions; otherwise, their prescriptions are limited to three per month.

STAR+PLUS has achieved success both with cost savings and with member satisfaction. One evaluation reported savings of \$78 million annually (8%) over projected costs. That same study reported a decrease of 22.8% in inpatient admissions (The Lewin Group, 2003). Another study reported a reduction of 38.5% in emergency room visits compared to a control group (Borders, Texas A&M, 2002).

Additionally, a member satisfaction evaluation revealed that 90% were satisfied or very satisfied with their care coordinator and 75-80% were satisfied when they called doctor's office for advice, appointment, tests or treatment (Shenkman, Institute for Child Health Policy, 2003).

Texas STAR+PLUS Success

\$78 million annual savings

38.5% reduction in ER visits

90% satisfaction

# Michigan

The state of Michigan serves its people with mental illness, addiction disorders and developmental disabilities through managed care contracts with its Community Mental Health Services Programs (CMHSPs) for what it calls "specialty services". These services are specific to these populations and are separate from Medicaid-funded medical services. Although individuals do not have a choice among plans, they do have choice among providers and services within the plan. CMHSPs are paid a monthly capitated fee for each enrollee based on historical costs for services (CMS Promising Practices, 2004).

Michigan law requires person-centered planning, a process for planning services based on an individual's strengths, choices and preferences, for publicly-funded specialty services. Each CMHSP must deliver a minimum set of services and may offer additional services, as needed by its enrollees.

Michigan developed a set of performance indicators for the CMHSPs before implementing managed care. Indicators measure access to services, readmission to inpatient settings, reporting, continuity of care, use of inpatient care, expenditures, cost per case, employment outcomes and other quality management indicators. Since beginning this managed care model, the indicators show an improvement in access to services, specifically in receiving services after assessment for non-emergency services. In addition, the number of Medicaid participants has not increased, even as the proportion of participants with severe and persistent mental illness has increased (CMS Promising Practices, 2004).

This model affords choice of provider and services and mandates person-centered planning through a local community mental health services plan. People are served when they need support regardless of setting.

# **Individualized Budgets**

## **Arkansas**

Arkansas is one of the three (3) states, along with New Jersey and Florida, which has been part of the Cash and Counseling Demonstration. This demonstration program has been sponsored by the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services and the Robert Wood Johnson Foundation. The program was evaluated, in part, by using a control group being served with traditional Medicaid personal care services from a licensed provider agency contrasted with a "treatment" group which received a cash allowance based on needs, along with assistance in managing the funds. The "treatment" group participants have great flexibility to hire whomever they want to provide personal assistance and can purchase assistive technology, appliances and home modifications. The counseling/fiscal agencies offer a wide variety of services to help people manage their cash including assistance in establishing the required budget plan, developing a plan for back-up support, and training people to hire and manage their own caregivers. They also make contact with participants each month and do reassessments every six (6) months to ensure care needs are being met (CMS Promising Practices, 2003).

Initial results from the demonstration showed higher satisfaction rates for overall care arrangements and quality of life, significantly higher than people in the control group. Because monthly cash allowances were approximately equal to the cost of Medicaid personal care services that people would otherwise have received, Arkansas reported no increased cost for providing the cash benefit in lieu of traditional personal care services (CMS Promising Practices, 2003).

# Oregon

Oregon's Independent Choices Program is also a Medicaid 1115 demonstration waiver which allows people qualified for Medicaid home and community-based services to receive cash in lieu of authorized in-home services. The program is limited to 300 people during the initial demonstration. Participants are assessed as all others who wish to qualify for Medicaid HCBS services. The value of the needed services is then converted into a cash equivalent which is sent to the participant's bank account every month. Participants must complete a ten hour training session and pass an exam in order to be eligible to complete payroll requirements. If the person or a designated surrogate cannot pass the test, a fiscal intermediary must be employed for payroll functions. Up to six (6) hours additional training per year can be requested and received. During the first year of enrollment, only five (5) participants needed fiscal intermediary services. In addition, spouses can be employed as caregivers, normally prohibited under Medicaid law (CMS Promising Practices, 2003).

Initial evaluation results of the demonstration are not yet available, but this program is a bit unique as it assumes that participants want, and have the ability, to control a cash allowance and fiscal intermediaries only support a payroll function.

# **Independence Plus Waivers and Self-Direction**

In 2002, CMS launched the Independence Plus Initiative to afford Medicaid participants and their families increased choice and control over their own services and supports. Independence Plus is based on the experiences and lessons learned from states that have pioneered the philosophy of consumer directed care, including the very successful "cash and counseling" demonstrations. Evaluation results demonstrated a higher level of member satisfaction than with traditional programs with no increase in expenditures.



The Independence Plus Initiative expedites the process for states to request waiver or demonstration projects. The Independence Plus Waiver programs allow participants to design a package of individualized supports, identify and attain personal goals, and supervise and pay their caregivers. CMS has approved eleven Independence Plus waivers, including eight 1915 (c) Waivers (New Hampshire, Louisiana, South Carolina, North Carolina (2), Maryland, Delaware, and Connecticut) and three 1115 Waivers (California, and Florida and New Jersey which are extensions of the original "cash and counseling" demonstrations). Two other states have 1115 self-direction demonstrations similar to Cash and Counseling (Oregon and Colorado), and a multitude of states offer self-directed program options under their section 1915(c) home and community based waivers (McClellan, 2005).

# **Methods to Ensure Budget Neutrality**

State policy makers are appropriately concerned about the potential costs of allowing greater individual choice of services and settings. The concern most often voiced is that while current long-term care financing is being shifted to follow an individual's desire to be served in the community, additional people requiring new financing will be admitted to nursing facilities. States fear that they will wind up paying for additional community services for individuals they currently serve and as well as for institutional services for additional people who are still being admitted to nursing facilities.

In a short paper supporting President Bush's FY 2004 Money Follows the Person Rebalancing Initiative, CMS addressed this issue directly explaining the impact of people moving to a community setting from a nursing facility. "Even if the vacated bed is re-filled, (a) some beds will not be re-filled, depending on current occupancy levels, (b) if re-filled, there will be some time before the bed is refilled, (c) for nursing facilities, most beds are initially refilled with private pay individuals who only gradually spend-down [to Medicaid eligibility]" (CMS, 2003a).

Many of the states discussed above, which have made investments in building their capacity to serve older adults and individuals with disabilities in community settings, have continued to see decreases in their Medicaid nursing facility utilization rates. In addition, Texas, which only recently adopted a "money follows the person" initiative, has not experienced any change in its steady decrease in nursing facility occupancy.

It is instructive to review some of the methods that have been and can be used by a state to ensure the budget neutrality of a rebalanced system.

# Combine Institutional and Home and Community-Based Care Budgets

Some states have chosen to combine their institutional and home and community-based care budgets and allow state agencies to manage the entire long-term service system based on an individual's needs, not just whether there is sufficient money budgeted for a particular setting. In this system, it is financially important for a state agency to ensure that people are served within the total budgeted amount. It is less important where people receive services. An individual's care needs are assessed, resources allocated and decisions made by the individual about the setting to receive those services. Oregon and Washington have both adopted this system for many years and have placed responsibility for managing the combined system under one administrative state entity. As noted above, both states have continued to reduce their Medicaid nursing facility utilization rates.

# Provider Reimbursement Across Institutional and Home and Community-Based Services

A number of states discussed above have decided to contract with provider organizations to coordinate care for individuals across both institutional and home and community-based services. Many of the states are paying providers a predetermined capitated amount per month for each enrollee. In these systems, there is a clear incentive for providers to purchase services in the most cost-effective manner and in the most cost-effective settings. Providers would have no reason to oppose individuals receiving services in a community setting, as long as they were able to do so. Although the degree to which consumer preference is considered differs in these systems, Arizona, Michigan and Wisconsin are all examples of these systems, as well as the many Program for All-Inclusive Care for the Elderly (PACE) models operating in states throughout the country, including Tennessee.

# **Budget and Waiver Caps**

Medicaid home and community-based waivers, by design, are limited in the number of people to be served. A state could decide to link growth in community-based waiver "slots" and expenditures to a similar reduction in institutional spending, as Vermont did in the mid-1990's, or as Wisconsin did when it passed a law specifying that if a nursing facility voluntarily "de-licensed" a nursing facility bed, a new home and community-based waiver opportunity could be created without going through the state budget process (CMS, 2003b). A state could also mandate expenditure limits for the nursing facility budget, the home and community-based services budget or cost-sensitive portions within those budgets.

Many states have used provider reimbursement to discourage or encourage long-term care growth within budgetary constraints. Over the years, states have worked hard to limit institutional expenditures and reimbursement by refusing to support the costs of unused beds, paying less for residents who don't require extensive medical care and ensuring a vigorous pre-admission screening program. States have also used reimbursement to encourage growth of community-based care capacity, as Oregon did in the late 1980's when it set a relatively high rate to encourage the growth of assisted living facilities as an alternative to nursing facilities.

# Prevent the Addition of Medicaid-Certified Nursing Facility Beds

Many economists believe that one effective method for decreasing expenditure growth is to limit the supply of a commodity or service. Most states have enacted either a certificate of need program for nursing facility construction or major renovation, a moratorium on the construction of new beds or on the Medicaid certification of additional beds, or a combination of these. As of 1998, thirty-eight (38) states had a certificate of need (CON) program that reviewed the need for new nursing home beds (Weiner, 2000). With the growth in the size of the elderly population and its projected continued growth, many of the CON applications resulted in litigation, since it was difficult for a state to justify that beds would not be "needed". Some states took a more direct approach to limiting supply and enacted moratoria on new nursing home construction or certifying additional Medicaid beds. As of 1998, nineteen (19) states had moratoria on additional nursing home beds (Weiner, 2000). One study of the change in nursing home supply between 1981 and 1993 concluded that CON and the moratoria significantly reduced the rate of growth in the number of nursing home beds (Harrington, 1996).

# **Convert Nursing Facility Beds to Community Care Facilities**

As discussed above, many states have taken action to limit the supply of nursing home beds. A few states have developed programs to encourage nursing facilities to convert their existing facilities to assisted living or other residential models (Nebraska, Iowa, and North Dakota). The most successful program was developed and implemented in Nebraska.



In 1998, the Nebraska legislature created the Nursing Facility Conversion Cash Fund with the express goal of giving nursing home owners financial incentives to convert all or part of their existing businesses to assisted living or other alternatives under the state's HCBS Waiver (Final Report, 2004). Grants were available up to \$1.1 million if owners agreed to reserve 40% of the newly constructed units for Medicaideligible residents, reduce the number of nursing facility beds by at least the number of new assisted living units created and operate as an assisted living facility for at least 10 years. There was a 20% matching requirement for non-governmental owners and the grant money could be used for construction, start-up costs, training expenses and first-year operating losses.

The final report on the program was issued in 2004. The report reveals that most of the funds were used to convert facilities to assisted living (\$49.9 million). Grant funds of \$3.1 million were used for conversion to respite care units or adult day care centers. In all, 969 assisted living units were created, 27 adult day care centers were established, 14 respite care units were constructed and 969 licensed nursing facility beds were retired. In a section marked cost effectiveness, the state asserts the following argument: Most of the grants were awarded in rural areas where the average Medicaid daily rate for nursing facility care is \$70/day; Medicaid assisted living costs are \$37/day. Based on the expected creation of 484 Medicaid assisted living units through 2001 (out of 969 total), the estimated annualized Medicaid savings are \$5.8 million, resulting in a 100% return on total investment in 9 years.

# Services

Another key building block is ensuring that needed services and supports are available across settings and provider types. To achieve a more balanced system, many states have worked to develop an increasingly market-based approach which allows individuals more choice over the location and type of services they receive and have the financing move with the person. By making the **individual** the focus of decision-making about the methods by which services are organized, he or she is able to make more cost-effective decisions.

States have invented many methods to assure that all services are mobilized to support what the individual needs and prefers, are effectively coordinated, and include emergency back-up arrangements to prevent breakdowns in services. CMS highlights the need to have services effectively coordinated, either by a single organization charged with that responsibility (Arizona, Michigan) or through a self-directed service option, where consumers purchase and direct their services (CMS, 2003b). Some states have adopted a "flexible service organization" where a single organization is responsible for all supports and can make adjustments to services as needed. Even though there may be multiple providers involved, one overarching organization is responsible to ensure that all services work effectively together and that new services are developed or adapted when needed by the individual. In some cases, states have developed the concept of having a single organization responsible for ensuring the adequacy of services, while including a comprehensive self-directed service option (Oregon). Examples of promising state practices are states listed as those with "seamless financing" such as Michigan, Oregon and Wisconsin discussed above and those with self-direction and person-centered planning such as the cash and counseling states, Michigan and Oregon also discussed above.

Recruitment and retention of direct care workers and developing an adequate supply of affordable and accessible housing are exceedingly important components of this building block.

As described below, there are a number of state and federal initiatives worth noting in both the workforce and housing areas.

# **Long-Term Care Workforce**

Individuals can only effectively choose the services they need and desire, in the setting of their choice, when those services are available in sufficient capacity. States across the country have identified the recruitment and retention of long-term care direct support workers as a major issue presently and one of increasing importance in the future. The reasons are driven by estimates that the number of people who need long-term care in the next 15 years will increase by 30% and that the number who may use paid long-term care services could double between the years 2000 and 2050 (Friedland, 2004). To meet this demand, the rate of growth in the long-term care labor force would need to grow, at a minimum, by more than 2% a year from 2000 to 2050. However possible this may seem, the working-age population is only expected to grow by 0.3% per year during this period. There will also be markedly fewer adult children per parent over the next 50 years (Friedland, 2004). This issue is not just a future challenge. During 2000-2010, it is estimated that the population age 85 and older will increase by 37%, while the population aged 25-54, the large majority of paid and family caregivers, is not expected to increase (Paraprofessional Healthcare Institute, 2001).

Most states are engaging in activities to address workforce needs. Some are concentrating on making this type of employment more attractive through increased wages and benefits, better working conditions and more opportunities for education and training. Others are working on retention issues such as career advancement, peer mentoring and workplace culture and supervision. But more and more, all states recognize this as an increasingly vital issue.

2000-2010 Population Growth Estimated				
Age 85+	37%			
Aged 25-54	0%			

Below is an example of what two states have done to address this issue.

# Massachusetts

The Metro Region (including Boston) of the Massachusetts Department of Mental Retardation (DMR) initiated a recruitment campaign for direct support professionals to address the desires of increasing numbers of individuals with developmental disabilities who wanted to live independently. DMR and about twenty-five (25) provider agencies hired a communications company to develop and manage the recruitment campaign, implement strategies and create all marketing tools. From the beginning, DMR wanted not only to address the current recruitment needs, but also to publicize the fact that existing professionals were making significant contributions to support the independent community living of individuals with disabilities. DMR hoped that the positive public messages would also help future recruitment needs (CMS Promising Practices, 2003).

To develop the campaign, the communications company surveyed the participating agencies on the recruitment techniques it had utilized and their perceptions of which had been successful. The company also conducted extensive interviews with direct support professionals to understand what factors motivated them to stay in this type of position. The consistent message was that workers who stayed in these jobs did so because they felt they were making a difference in peoples' lives and the work was deeply and sincerely appreciated by people with disabilities, their families, supervisors and co-workers. The campaign's theme "Some people are lucky enough to love their work" was developed directly from the research.

The campaign kickoff was centered on agency administrators honoring their outstanding staff and the staff telling the stories of their rewarding work. The event was covered by television, radio and newspaper media and an informational brochure and posters were produced and publicized. In the following months, providers sent posters and other materials to libraries, job centers, churches, senior centers and other distribution points within the region. In addition, a direct mail campaign was initiated, newspaper

advertising purchased, radio and print media were utilized to continue focus on the positive stories of existing workers, and a job fair promoting the provider agencies was held. A web site was also developed to assist recruitment, as was a toll-free telephone number.

During the first year of the campaign, about 2,000 inquiries were generated and provider agencies hired about 200 people over eighteen (18) months. After this initial success, DMR expanded the campaign to other parts of the state. In 2001 and 2002, the campaign received nearly 8,000 inquiries and about 400 new workers were hired (CMS Promising Practices, 2003).

More recently, the web site has been enhanced and now allows older adults and individuals with disabilities the opportunity to find staff directly through the site or by calling the toll-free number. The job application on the web site asks several questions that allow people seeking staff to search the database to meet specific criteria such as language spoken, geographic area, willingness to drive, hours of work and experience (CMS Promising Practices, 2004).

This is an excellent example of a relatively inexpensive coordinated campaign to recruit new direct support professionals. Other states are in the process of adopting at least parts of this initiative.

# Virginia

The Jefferson Area Board on Aging, an area agency on aging in central Virginia, partnered with two local hospitals, two training centers, a social services organization and a pharmacy to establish a Nursing Assistant Institute (NAI) to address both a shortage of personnel and high turnover rates. The NAI supports nursing assistants in multiple settings including hospitals, nursing homes and individual homes. Programs have been developed to increase recruitment and improve retention including continuing education programs, recognition programs and workplace culture change consulting (CMS Promising Practices, 2003).

On the recruitment side, the NAI provides scholarships to pay for Virginia's 120-hour training course to become a certified nursing assistant (CNA) and stipends to cover the costs of the licensure examination fee. Licensure is only required to work in a nursing facility, but individuals who take the training course also go to work in a variety of other community settings.

NAI has developed a continuing education program, based on surveying both current CNAs and nursing supervisors, which includes topics such as improving communications skills with managers, wound prevention and stress management. The Institute contracts with local instructors and long-term care facilities to provide these sessions free or at low-cost. NAI also trains experienced CNAs on becoming mentors for new CNAs.

NAI also develops and operates programs to improve recognition for nursing assistants and provides consulting services to providers in implementing culture change based on the principles articulated by the Pioneer Network. These principles include developing plans of care based on the individual needs and desires of the individual and assigning staff based on their unique skills and talents. NAI also focuses on lobbying for better wages and benefits for CNAs.

Although there has been no formal evaluation of these programs, there are indicators of success including increases in the number of people taking nursing assistant training, and higher levels of job satisfaction and preparedness after completion of continuing education training.

This is another example of a coordinated recruitment and retention campaign addressing both the direct support worker and the supervisor, each important contributors to recruitment and retention.



#### **Family Caregivers**

For many years, a number of states have increased the supply of in-home caregivers by paying family members of an individual needing support. In Medicaid waiver programs, family members can be paid as caregivers, with the exception of spouses and parents, otherwise excluded from payment as "legally responsible adults". In Oregon's Medicaid Waiver program for older adults and individuals with physical disabilities, one of the first questions asked after a person is found eligible for waiver services and a plan of care is developed, is if the person receiving services knows of a friend or family member who could help provide services. This has lead to a significantly increased supply of in-home caregivers.

In addition, the National Family Caregiver Program (NFCP) was enacted in November 2000, recognizing the need to support adult family caregivers of functionally dependent individuals over 60 and caregivers over 60 who are grandparents or other relatives of children under 18 needing long-term services. This landmark legislation recognizes the need to support families who need assistance to continue to care for their loved ones.

Below is a description of Pennsylvania's work in this area prior to the enactment of the NFCP and how it is integrating the new national funding with its existing state program.

#### Pennsylvania

The Commonwealth of Pennsylvania began its Family Caregiver Support Program with a four county pilot program in 1987 and expanded it to a statewide program in 1990. The program's services were targeted at supporting primary family caregivers of relatives with disabilities age 60 and older who were unable to perform some activities of daily living (ADLs) or under age 60 with chronic dementia. Caregivers must be related by blood or marriage and must live together.

Services begin with an assessment of a family's needs by a specially trained social worker who develops a care plan. The social worker also provides information about federal and state programs, Medicare

supplemental and long-term care insurance, caregiver support groups and techniques for better care giving (CMS Promising Practices, 2004). The assessment is the same one used to determine eligibility for several other HCBS programs and social workers can assist in the application process.

Regardless of household income, a caregiver and a care receiver can receive help from an Area Agency on Aging through Older Americans Act funding. However, if the household income is below 380% of poverty, caregivers can receive up to \$200 a month reimbursement for a range of supplies and services including: respite care; counseling; durable goods; caregiver education and training; care planning and management. They can also receive one-time grants up to \$2000 to modify a home or purchase assistive devices.

The National Family Caregiver Support Program will allow similar services to be provided, but will broaden the focus to allow non-relatives and not requiring that they reside in the same household.

The existing program serves about 6500 families per year and expenditures were \$11.5 million annually for FY2001-2003. Costs average approximately \$2900 for a full year and the average length of stay in the program is a little more than 8 months (CMS Promising Practices, 2004).

Pennsylvania Family Caregiver Support Program

6500 families served annually

\$2900 annual average cost per family

# **Federal Government and Foundation Grant Support**

In July 2003, the Robert Wood Johnson Foundation and The Atlantic Philanthropies announced that they had awarded \$7 million to five (5) state-based coalitions to carry out demonstration projects under their "Better Jobs, Better Care" initiative, a program to improve the recruitment and retention of quality direct care workers. In September, the same foundations awarded \$3.8 million to eight (8) research institutes to conduct applied research and evaluation studies under the Better Jobs, Better Care program. The national program office, based at the Institute for the Future of Aging Services, is providing program support and direction and will help translate research findings to policymakers, practitioners and advocates throughout the country. Outcomes from this research are beginning to be reported (www.bjbc.org).

In October 2003, the U.S. Department of Health and Human Services announced five (5) demonstration grants totaling nearly \$6 million aimed at helping recruit, train and retain direct service workers. Three of the projects are geared to demonstrating the efficacy of offering health insurance to direct service workers and the other two are focusing on developing educational materials, training of service workers, mentorship programs and other activities. In 2004, about \$5.5 million in grants were awarded to five (5) entities, three of which were going to demonstrate the impact of offering health insurance to direct-service workers and two which were for developing educational materials, training and mentorship programs. No data is yet available from these projects (www.cms.hhs.gov).

#### Housing

Another vital service needed to achieve a balanced long-term service and supports system is having sufficient access to affordable, accessible housing. In the examples below, it is evident that states have addressed this issue in a variety of ways.

### Wisconsin

Wisconsin developed a supported housing initiative shortly after beginning a Medicaid waiver for people with developmental disabilities called Community Supported Living Arrangements. The waiver was targeted to people who owned or controlled their living environment, including being party to a lease. Access to safe, affordable and accessible housing quickly became a vital part of the program's viability (CMS Promising Practices, 2003).

As part of the supported housing initiative, the state hired a supported housing specialist. Initially geared to the new waiver, the specialist now serves people with developmental disabilities and people with brain injuries in three different Medicaid Waiver programs. The specialist works with individuals with disabilities and their families to find individualized housing solutions which can include home ownership, relocation from a nursing home, and transitional housing for a homeless family which includes a child with a disability.

In the beginning of this program (1992) most of the work done by the supported housing specialist involved working one-on-one with individuals and families. Now the specialist works more and more on building local safe, affordable and accessible housing capacity. In the beginning, presentations were made to housing providers all over the state and consumers learned about available help mainly from those providers. Today, housing agencies, case managers, the state's web site and satisfied parents are all sources of information and referral for the program. The specialist has also authored or co-authored many materials on supported housing including home-buying and new construction guides for people

with disabilities, and a booklet series on issues related to renting or owning a home, including income supports and the impact on public benefits.

Some specific outcomes include helping income-eligible individuals with disabilities to purchase homes and fund individualized housing solutions. In addition, the state points to developing 33 units of rental housing for people with disabilities, a 20 unit mixed-income condominium development in which 5 were designed and sold to households in which one member has a disability. Also cited was a new rural rental development specifically designed to be accessible and affordable to people with disabilities (CMS Promising Practices, 2002).

#### Massachusetts

The Massachusetts legislature mandated the establishment of an "Accessible Housing Registry" as part of a Housing Bill of Rights for Persons with Disabilities to address the common need of accessible housing owners and people needing accessible housing to connect with one another when an accessible unit is vacant. The law requires all property owners, managers and housing authorities to actively market units to people with disabilities. It also requires owners to inform anyone who has contacted them about an accessible unit when a vacancy arises, and register vacant units with Mass Access and hold those units for at least fifteen (15) days during which the unit can only be rented to a person with a disability who needs the accessible features of the unit (CMS Promising Practices, 2003).

The registry has been operational since 1995 and houses information about vacant accessible housing units, including public, private subsidized and market-rate developments. The registry also contains information on non-accessible units to allow individuals with disabilities who do not need an accessible unit to also conduct a search. Property managers can list vacancies at no cost. The registry contains much useful and relevant information on each housing development with links to the development's web page. People can search by region or community, by rental price range, bedroom size, accessibility status and other features.

New developments are added each year, but updates on vacancies in listed developments are done monthly. Expected vacancies and projected occupancy dates can also be reported and the process can be accomplished electronically. Massachusetts continues to support the maintenance of the database and Web site with \$100,000 a year in state funds.

The results from 2002 show 541 vacant accessible units reported, tracked and marketed and about 2000 Web visits per month. An earlier (2000) survey of property managers found that the registry reduced vacancy rates and that there was an increase in the number of accessible units rented to people who needed that specific feature. In addition, housing advocates reported using the registry to help people find appropriate housing (CMS, Promising Practices, 2003).

The registry is clearly a useful tool for both owners and renters. The challenge for the model is that the data needs to be continually updated with vacancies and new accessible units.

#### Arkansas

Arkansas constructed an affordable assisted living residence consisting of 45 units, all of which are available to individuals who qualify for Arkansas' Medicaid HCBS Waiver. The project was developed under the Robert Wood Johnson Foundation's Coming Home Program, an affordable assisted living demonstration program.

This project demonstrates excellent collaboration between housing finance and development agencies and LTC service agencies and providers at the state and local level. From the state housing side, the



Arkansas Development Finance Authority agreed to set aside Low Income Housing Tax Credits and HOME funds, both federal development programs, to support the project and publicized the availability of predevelopment funds and state and federal tax credits for the project. On the state services side, the Division of Aging and Adult Services helped enact legislation governing the assisted living industry and created regulations to implement the legislation. It also applied for and received approval for a new Medicaid HCBS Waiver to cover services in assisted living.

On the local level, the Community Development Corporation of Benton-ville/Bella Vista, Inc. recognized the need for assisted living and while it had experience developing housing, it had no experience providing personal care and health services. It found a service provider, Mercy Health Systems of Northwest Arkansas, who was willing to provide services to assisted living residents and was already delivering similar services to Medicaid enrollees in that area.

Arkansas
constructed
an affordable
assisted living
residence
available to
individuals who
qualify for
Arkansas'
Medicaid HCBS
Waiver.

Below are some interesting data about the residents who had moved into the residence, six months after its opening:

- 91% of the residents were from that county
- 73% were Medicaid enrollees
- 56% moved from a private home, alone or with spouse
- 24% moved from a private home, with family
- 15% moved from a residential care facility
- 5% moved from a nursing facility
- 49% had mild cognitive impairment or dementia
- 93% were incapable of administering their medications
- 67% would have gone to a nursing facility if affordable assisted living had not been available (NCB Development Corporation, 2005)

As of November 2005, there are two additional projects under construction and five additional projects in development. The NCB Development Corporation has been assisting the state of Arkansas in its efforts as the National Program Office for the Coming Home Program.

# Quality

Quality is one of the key building blocks listed by CMS for coherent systems management of long-term care services. It is clear that policymakers want quality services in every aspect of long-term care and states have developed varied systems to define, measure, assess and improve quality. Some states have focused their attention more on system performance indicators like Michigan (discussed above) and others have been more focused on consumers' perception of quality. Below are examples of two different survey instruments which focus on the perception of quality from the care-receivers' perspective.

#### Indiana

Indiana developed a Quality Improvement Process (QIP) survey which is administered to at least a 5% sample of Medicaid, state and federally-funded program participants on an annual basis. The automated program surveys in five different domains: consumer choice; timeliness; respectfulness; consistency; and task performance. It asks participants to respond with answers that range on a 5 point scale from always to half the time to never (CMS Promising Practices, 2003).

The data is used to trigger special reviews when a serious incident is identified or when the respondent gives negative answers on trustworthiness. A case manager investigates and reports findings to the state agency. Corrective action is taken if needed.

The data is also used to give provider-specific feedback in aggregated and summary form. To protect the anonymity of participants, no scores are given to a provider unless at least five (5) surveys are completed.

The state combines this consumer feedback with monitoring by the area agencies on aging, the designated case management entities, which are required to make home visits every ninety (90) days to ensure that the plan of care continues to meet the needs of the program participant. The area agencies also submit annual quality improvement plans. The state agency also establishes standards for the state program and Medicaid waiver services it administers and monitors case management operations, including random review of participant files and visits to participants' homes (CMS Promising Practices, 2003).

This is a good example of a state which sets standards, monitors those standards and asks consumers directly about their experiences with service quality.

## **CMS Participant Experience Survey**

CMS contracted with The Medstat Group to design a technical assistance tool for states which surveys participant feedback on home and community-based services for frail elders and adults with physical disabilities (PES E/D), adults with mental retardation and/or developmental disabilities (PES MR/DD) and adults with acquired brain injuries (PES BI). The survey was designed to be administered in-person and can generate thirty-three (33) performance indicators. The initial surveys and relevant users' guides were released in late 2003 and are available online. CMS has also released software automating the PES E/D and the PES MR/DD which allows interviewers to enter responses onto laptops and then collate all the interviews into a master database (Galantowicz, 2005).

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The Participant Experience Survey has four priority areas of interest and includes some of the following indicators:

- 1) Access to Care-documents unmet needs in bathing, dressing, transferring, eating, toileting, meal preparation, groceries, housework, laundry, medication administration, transportation, staff time and adaptive equipment/environmental modification.
- 2) Choice and Control-documents unmet demand for choosing and directing care staff, ability to change care staff, staff problems, case manager contact and interaction.



- 3) Respect/Dignity-documents respect and listening by various program staff, verbal and physical abuse and theft.
- 4) Community Integration/Inclusion-documents unmet need for community improvement, unmet demand for employment, control over choice of employment and job satisfaction.

Since the Participant Experience Survey is available for free in the public domain, it is hard to know exactly how many states have implemented the PES for one or more of the populations it serves. The Medstat Group estimates 8 states have implemented the PES, 5 are planning to implement and coordinating with Medstat and another 7 have indicated interest by requesting software passwords (Galantowicz, 2005). Tennessee should definitely explore using this developed resource, free of charge to the state.

# **Conclusion and Policy Recommendations**

The state of Tennessee has initiated a number of programs and activities over the last 4-5 years that should allow additional opportunities for individuals to have the choice of receiving long-term care (LTC) services in their homes. It has implemented new home and community-based services (HCBS) programs for older adults and adults with physical disabilities: the state-funded Options program; the Medicaid HCBS Waiver; and the Program for All-Inclusive Care for the Elderly (PACE) in the Chattanooga area. The Area Agencies on Aging and Disability all provide information and assistance for LTC services and have a statewide toll-free telephone line. The state has consolidated responsibility for all LTC budgets within TennCare's Division of Long Term Care. Tennessee is supporting the development of 2 pilot Aging and Disability Resource Centers and 2 managed LTC programs. It is also developing a new client assessment instrument and process for accessing Medicaid LTC services.

Additionally, in 2005, the Legislature unanimously passed, and the Governor signed, Senate Joint Resolution 57 calling on the Governor to develop a new LTC services plan which included the "entire range of care and support, from respite care in the home and adult day care services to care in residential settings", the "elimination of artificial barriers to appropriate care…through the creation of a global long-term care budget" and the "enhancement of long-term care information, referral information and coordination of services…in an effort to provide a single entry point for simple, consumer-friendly access to long-term care". This is a strong acknowledgement of some of the barriers individuals confront in accessing the services they want and where they want them delivered, in addition to calling for actions to remedy them.

Acknowledging all that has recently been accomplished, all the work in progress and all the plans being considered, Tennessee is behind most states in the country in affording timely choices to a range of LTC services desired by its adult residents with disabilities. Below are one overarching and 15 additional recommendations for improvement. These recommendations follow the format used by CMS to analyze "coherent systems management" of a long-term services and supports system: access, financing, services, and quality.

These recommendations can be implemented incrementally and should result in an improved LTC system—one that supports individual choice, personal and governmental accountability, efficiency, affordability and sufficient high-quality services.

#### **Overarching Recommendation**

First, the Governor should develop and implement programs which reflect legislative action, such as Senate Joint Resolution 57 (2005), which states in part that Tennessee should have a "long-term care system which offers Choices for Care to individuals and their families". This includes "the entire range of care and support from respite care in the home and adult day care services to care in residential settings, including assisted care living facilities" and "eliminates artificial barriers and funding biases through the creation of a global LTC budget or other mechanism" (SJR 57).

#### Access

1. Continue the development of a single entry point (SEP) system through the Tennessee Commission on Aging and Disability and the Area Agencies on Aging and Disability. An SEP

- should be designated for a specific local area where people can access information about LTC services, receive counseling about options and service availability, assessment of need, and eligibility determination for public programs. The SEP and its database of LTC resources should also be able to be accessed electronically and coordinated statewide. SEP staff should travel to people seeking assistance rather than requiring people to come to a specific site.
- 2. Continue the development of a client assessment instrument that focuses on the need for supports that address activities of daily living as much as medical needs. That instrument should be geared to electronic data collection which determines program eligibility, develops plans of care for nursing facility and community-based care, and links with existing program and finance information systems.
- 3. Ensure that information is available for people in need of LTC services at hospitals and a short time after admission to a nursing facility so that people understand their LTC options. Eligibility determination needs to be done much more efficiently, so that people receive timely notice if they qualify for public programs. This can be accomplished in many ways, including through a "fast-track" process or using a form of presumptive eligibility where an individual could begin receiving HCBS pending a final determination of financial eligibility.
- 4. Develop a post-admission nursing facility assessment process for Medicaid residents and those soon to be eligible for Medicaid which informs individuals and families of HCBS options and assists people who want to have services delivered in another setting. This process should begin no later than 30 calendar days after facility admission. Responsible entities must be designated and be accountable for assisting people to leave facilities, and transition costs need to be funded as necessary.

### **Financing**

- 5. Designate a lead entity and fund an ongoing program to educate residents about individual financing of long-term services and supports. The program should use a broad variety of educational media to target younger, working-age adults with a focus on savings and insurance programs, and older adults with a focus on health promotion and disease prevention and cost-effective home and community-based services.
- 6. Develop a plan for a unified long-term services expenditure budget that is flexible enough to allow an eligible individual to choose where to receive LTC services and supports. Although TennCare manages both institutional and HCBS Waiver budgets, it needs to develop mechanisms which allow easy transfer of monies from facility care to HCBS, and provide enough Waiver slots and services for individuals who want care delivered outside nursing facilities.
- 7. Continue development of the managed LTC pilot program and rigorously evaluate the impact on the population it serves. Special attention must be focused on timely access to needed services, the quality of the services delivered and appropriate consumer safeguards
- 8. Develop a statewide Medicaid HCBS Waiver program which enables individuals to direct their own service providers and have control over a specified budget.

#### **Services**

- 9. Adopt a variety of methods to encourage and sustain family caregiving through means such as compensating relatives for caring for their loved ones, providing in-home respite care and other supportive services, including caregiver training and education. The State should add assistive equipment/technologies to its Waiver services and utilize the existing minor home modification service whenever needed to allow an individual to continue to receive needed services in their home. Assistive technologies could include cost-effective items such as controls to turn lights on and off, eating utensils and door handles that are easy to grip and alarms which alert people when there is danger from leaving a stove on in a kitchen or when people are at the door or calling by phone.
- 10. Include assisted living, in-home respite care and adult day care services in the HCBS waiver and develop a limited personal care option in the Medicaid State Plan focused on people who need this service to maintain their independence in their homes.
- 11. Designate one public entity with the responsibility for recruiting and retaining needed LTC providers. Too often this responsibility is spread among various entities with predictable inefficient results. The State should utilize a variety of mechanisms, including enhanced reimbursement, to develop needed provider capacity.
- 12. Provide increased reimbursement for providers of home care services. Home is where the huge proportion of Tennesseans want to live as they age. Home care workers and their agencies must be reasonably compensated, supported with training and publicly acknowledged for their important work.
- 13. Develop affordable, accessible "housing with services" and other community living models and make that development a State priority. A lead entity must be designated and given the responsibility of ensuring that specific numbers of units are developed.
- 14. Ensure affordable and accessible transportation options in both rural and urban areas. People must be given the opportunity to be active members of their communities and be able to access friends and other supportive community entities. These activities help older adults and adults with physical disabilities remain healthy.

# Quality

15. Continue to develop systems designed to monitor quality and to detect and resolve problems in the LTC system, especially in the HCBS program. The consumer's voice must be brought into the evaluation of HCBS quality, as well as all other LTC settings, and Tennessee should explore using the Participant Experience Survey for this purpose. Appropriate data and management systems must be developed to support a quality assurance/quality improvement program.

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